Understanding health-care outcomes of older people with cognitive impairment and/or dementia admitted to hospital: a mixed-methods study

Emma Reynish, Simona Hapca, Rebecca Walesby, Angela Pusram, Feifei Bu, Jennifer K Burton, Vera Cvoro, James Galloway, Henriette Ebbesen Laidlaw, Marion Latimer, Siobhan McDermott, Alasdair C Rutherford, Gordon Wilcock, Peter Donnan and Bruce Guthrie

1Faculty of Social Sciences, University of Stirling, Stirling, UK
2School of Medicine, University of Dundee, Dundee, UK
3Deanery of Clinical Sciences, University of Edinburgh, Edinburgh, UK
4Health Informatics Centre, University of Dundee, Dundee, UK

*Corresponding author Emma.Reynish@stir.ac.uk

Declared competing interests of authors: Peter Donnan reports grants from Shire Pharmaceuticals Ltd (London, UK), Gilead Sciences, Inc. (Foster City, CA, USA) and Novo Nordisk (Bagsvaerd, Denmark) outside the submitted work, and that he is a member of the New Drugs Committee of the Scottish Medicines Consortium. Vera Cvoro reports receiving funded space from the European Stroke Organisation at the European Stroke Organisation Conference 2017, outside the submitted work.

Published April 2021
DOI: 10.3310/hsdr09080

Scientific summary

Outcomes of older people with cognitive disorders
Health Services and Delivery Research 2021; Vol. 9: No. 8
DOI: 10.3310/hsdr09080

NIHR Journals Library www.journalslibrary.nihr.ac.uk
Scientific summary

Background

People with dementia and other disorders resulting in confusion are an important subset of frail older people who present specific challenges, particularly when admitted to acute hospitals. The Department of Health and Social Care and the Royal College of Psychiatrists have estimated that two-thirds of hospital beds are occupied by patients aged $\geq 65$ years, up to half of whom might have some kind of cognitive impairment, including dementia and delirium.

In the hospital setting, cognitive impairment may be due to a number of overlapping conditions. People may have pre-existing dementia before admission, may develop delirium (characterised by an acute onset of confusion, a fluctuating course and inattention) as part of the acute illness precipitating admission or may have delirium superimposed on dementia. Finally, unspecified cognitive impairment due to undiagnosed dementia or delirium, adverse effects of medication, poorly controlled physical morbidities (e.g. diabetes mellitus) or a combination of these is also common. The symptoms and presenting features of all of these conditions show considerable overlap, which can lead to misdiagnosis; for example, the onset of neuropsychiatric symptoms in a patient with dementia may be labelled as worsening of their dementia rather than be properly attributed to delirium. We therefore use the term ‘cognitive spectrum disorders’ to signify the presence of cognitive impairment, whether formally diagnosed or not.

Older people admitted to hospital with a cognitive spectrum disorder are a heterogeneous and highly vulnerable population who are typically poorly assessed and managed, and it is important to understand their needs better in order to focus care and treatment. However, most research in older people admitted to hospital has studied either dementia or delirium in isolation and has been most commonly undertaken in relatively small cohorts of selected volunteers in specialist geriatric settings, risking selection bias and poor generalisability. Relatively few studies have examined outcomes in this population, particularly outcomes after discharge. Systematic reviews that separately examined dementia, delirium and delirium superimposed on dementia in hospital inpatients have been published. In these, prevalence varies depending on the population studied (e.g. specialist settings vs. unselected medical admissions; early vs. later assessment after admission, age range considered) and the assessment methods used, with dementia assessment not normally including a delirium screen, thereby increasing the risk of misclassification.

Objectives

The study sits in phase 0/1 of the Medical Research Council Framework for the Development and Evaluation of Complex Interventions, and will provide the baseline for the development of an intervention for evaluation in the future. The increased understanding resulting from this study is a component that is necessary for the next step in improving the quality of care for people with cognitive impairment in general hospitals.

The study aimed to improve the understanding of the outcomes of emergency hospital admission in people with cognitive impairment and/or dementia to support the development of a multidomain intervention.

The objectives of the study were twofold:

1. review of outcomes – review of current literature and a patient opinion survey to obtain an understanding of the quality and type of evidence that exists about the prevalence of cognitive impairment in older people admitted to hospital as emergencies and associations with a spectrum of outcomes assessed or measured in this domain, and elucidate the outcomes that are important to people who have experienced an acute hospital admission
2. analysis of outcomes – data linkage and analysis of a unique routine population-based health-care data set to measure health-care and economic outcomes following hospital admission of older people with and older people without cognitive impairment and dementia.

The research was conducted from January 2015 to June 2018 and used data from people admitted between 2012 and 2013.

Methods

The project used a systematic review of the research literature, a patient opinion survey and analysis of a unique large admission data set to examine health-care outcomes and costs for older people with cognitive impairment and dementia admitted as an acute medical emergency.

Review of outcomes

Systematic review
This involved database searches identifying peer-reviewed quantitative epidemiology measuring prevalence and associations with outcomes. Screening for duplication and relevance was followed by full-text review and assessment of quality, followed by a narrative review of the data.

Patient opinion survey
A survey sought opinion on the key outcomes for people with dementia and/or confusion, and their carers, in the acute hospital.

Analysis of outcomes


An analysis of the Older Persons Routine Acute Assessment data set measured associations between different patterns of cognitive impairment and outcomes.

Setting
A medical admissions unit in an acute hospital in one Scottish health board.

Participants
Older people (aged ≥ 65 years), with or without a cognitive spectrum disorder, admitted as medical emergencies between January 2012 and December 2013 who underwent a structured nurse assessment (Older Persons Routine Acute Assessment). ‘Cognitive spectrum disorder’ was defined as any combination of delirium, known dementia and an Abbreviated Mental Test score of < 8 out of 10 points.
Main outcome measures
Living at home 30 days after discharge, mortality within 2 years of admission, length of stay, re-admission within 2 years of admission and cost.

Data sources
Scottish Morbidity Records 01 data were linked to the Older Persons Routine Acute Assessment data set.

Older people admitted as medical emergencies in this Scottish health board have been routinely screened for cognitive impairment, delirium and dementia using structured instruments since 2011. This unique data set was linked to routine hospital and place of residence data by the University of Dundee Health Informatics Centre, and used to examine how a range of outcomes varied between those with and those without cognitive impairment, delirium on admission and/or dementia.

Results
The systematic review highlights the significant overlap in conditions of patients presenting to general hospitals with confusion (cognitive spectrum disorders). Methodological heterogeneity, especially concerning diagnostic criteria, results in some dementia cohorts including patients with concurrent delirium (delirium superimposed on dementia), some delirium cohorts differentiating between those with pre-existing cognitive impairment (delirium superimposed on dementia) and those with isolated delirium, and some cohorts screening using cognitive function alone.

Despite considerable methodological differences, cognitive spectrum disorders are common in the inpatient population over the age of 65 years, and are associated with significantly longer lengths of stay and worse survival in both the short and the longer term. Differences in outcomes between individual conditions are less clear and may benefit from some standardisation across conditions of diagnostic categorisation. This means that there is significant overlap in conditions of patients presenting to general hospitals with confusion.

The survey provides an insight into the challenges facing general hospitals in relation to an admission of a person with a cognitive spectrum disorder to ensure that the outcome is perceived as positive for the patient and their carers/family.

Although the overall expectation relating to health and well-being when discussing a positive outcome for this group of patients is no different to that for the general population, in that they wish to return home with the same functionality and cognitive ability as they had prior to the event that led to the admission, the focus for many, when asked about a positive outcome, is on the process of the actual hospital stay. The issues surrounding this highlight that there are some challenges here that the respondents felt were important to a positive outcome. So, failing being able to be discharged home in the same condition as at the time of admission, having a satisfactory experience of the admission was seen as a positive outcome.

From the analysis of the Older Persons Routine Acute Assessment data set, we found that 35% of people aged ≥ 65 years with an incident admission to the acute medical unit had a cognitive spectrum disorder. Delirium was present in 23.4% of admissions and dementia was present in 15.3% of admissions. Almost one-third of people with delirium and almost half with dementia had both delirium and dementia (7.6% had delirium superimposed on dementia). A further 4.2% of people who were admitted had unspecified cognitive impairment, defined as a low Abbreviated Mental Test score without known dementia or delirium. Cognitive spectrum disorders were strongly associated with low functional ability, with > 50% of patients with known dementia (either alone or superimposed on delirium) having a low activities of daily living score prior to admission (persistently low activities
of daily living scores) and almost 50% of patients admitted with delirium alone having a decline in activities of daily living scores from their functional status 3 months prior to admission (changed activities of daily living scores). Only 19% of people admitted with cognitive spectrum disorders had persistently high activities of daily living scores, compared with 58.2% of people admitted without cognitive spectrum disorders.

Outcomes in older people with cognitive spectrum disorders following hospital admission are significantly worse than in those without cognitive spectrum disorders. The proportion of people living at home 30 days post discharge was significantly lower among patients with cognitive spectrum disorders than among patients without cognitive spectrum disorders (81.7% vs. 93.4%). Delirium superimposed on dementia had the poorest outcome, with only 69.1% of people in this group living at home 30 days post discharge.

Mortality from the date of admission was high, with 52.6% of people with cognitive spectrum disorders dying within the 2-year follow-up period, compared with 33.5% of people without cognitive spectrum disorders. The presence of any cognitive spectrum disorders was associated with increased mortality over the entire follow-up period but with different temporal patterns depending on the type of cognitive spectrum disorder. Compared with people without cognitive spectrum disorders, delirium alone was associated with increased mortality risk in the 6 months after admission and 1 year from admission until the end of follow-up. Having dementia alone or delirium superimposed on dementia was not associated with mortality in the first 3 months, but was associated with higher mortality at 3 months to 2 years post admission. Having unspecified cognitive impairment was not associated with mortality in the first 6 months post admission, but was associated afterwards.

Re-admission at the 2-year follow-up was high, with 65.6% of people with cognitive spectrum disorders being re-admitted within 2 years, compared with 60.1% of people without cognitive spectrum disorders. At the end of the 2-year follow-up, 13.2% of patients with cognitive spectrum disorders died without being re-admitted, compared with 5.3% of patients without cognitive spectrum disorders. Compared with people without cognitive spectrum disorders, delirium alone or dementia alone was associated with increased re-admission risk during the whole follow-up period. Having delirium superimposed on dementia was not associated with an increased risk of re-admission in the first 3 months, but was associated with a higher risk of re-admission at 3 months to 2 years post admission. Having unspecified cognitive impairment was not associated with an increased risk of re-admission at any time after discharge.

Finally, older people with cognitive spectrum disorders have an average length of stay of almost 25 days, compared with 12 days in those without a cognitive spectrum disorder. Length of stay in people with cognitive spectrum disorders varied depending on the type of cognitive spectrum disorder, with hospital stays for people with delirium superimposed on dementia being more than three times longer than stays for people without cognitive spectrum disorders, and stays were almost twice as long for people with delirium alone, dementia alone or an unspecified form of cognitive impairment.

When hospital costs were examined for patients with and patients without cognitive spectrum disorders, both cross-sectionally and longitudinally, we found that patients with cognitive spectrum disorders had significantly higher hospital costs at their incident admission than non-cognitive spectrum disorder patients did. However, if we looked at it from a longitudinal perspective, the cost of patients with cognitive spectrum disorders, particularly those with delirium superimposed on dementia or unspecified cognitive impairment, cumulate at a lower rate than patients with no cognitive spectrum disorders. The cost difference between cognitive spectrum disorder and non-cognitive spectrum disorder patients generally became negligible in the long run. Moreover, we demonstrated that the cognitive spectrum disorder group was not homogeneous. Patients with different cognitive spectrum disorders might differ in their one-off incident costs, as well as in the growth rate of their cumulative costs, if examined longitudinally.
Finally, the study highlighted the importance of accounting for mortality while making longitudinal predictions of costs for patients with different conditions. In our case, patients with cognitive spectrum disorder tended to have a higher hazard rate of death than non-cognitive spectrum disorder patients did. If we ignore this while fitting a longitudinal model, we risk overestimating the cost growth rate of cognitive spectrum disorder patients and, accordingly, the differences in their cumulated totals.

Limitations

A lack of diagnosis and/or standardisation of diagnosis for dementia and/or delirium was a limitation for the systematic review, the quantitative study and the economic study.

Additional limitations of the quantitative study arise from the use of routine health-care data and the cross-sectional nature of the Older Persons Routine Acute Assessment. The following five areas are discussed in further detail in the description of the work: (1) coverage, (2) accuracy of brief assessment tools, (3) cross-sectional nature of assessment, (4) lack of full dementia diagnostic workup and (5) differences between admission and incident cohorts. The economic study was limited to in-hospital costs as we had no data for social or informal care costs.

The survey was conducted online, limiting its reach to older carers and those people with cognitive spectrum disorders.

Conclusion

The three distinct research methodologies used in this project demonstrate the consistent finding that patients admitted to hospital with confusion (whether due to delirium, diagnosed or undiagnosed dementia or a combination of these) have poor outcomes. The overlapping clinical manifestations and non-standardised diagnostic criteria for each of the individual cognitive spectrum disorders hampers our ability to synthesise evidence on each condition’s prevalence and associated outcome. When taking all cognitive spectrum disorders as a whole, over one-third of patients from the older population who are admitted to hospital have a cognitive spectrum disorder. When analysing the outcomes of the four mutually exclusive subgroups of the population with cognitive spectrum disorders (known dementia, delirium, delirium superimposed on dementia and unspecified cognitive impairment), outcomes remain poor and show no clear distinction between subgroups. Future research should include standardisation of case-finding and diagnostic criteria to aid stratification of cognitive spectrum disorders. Longitudinal research and analysis adjusting for physical comorbidity and function should examine whether cognitive impairment is an independent predictor of poor outcome or whether worse outcome is mediated by physical comorbidity, functional status or frailty. Finally, research designed to elucidate whether these poor outcomes are a result of the pathological processes themselves or the care delivered within the hospital setting will further our understanding of clinical management.

Study registration

This study is registered as PROSPERO CRD42015024492.

Funding

This project was funded by the National Institute for Health Research (NIHR) Health Services and Delivery Research programme and will be published in full in Health Services and Delivery Research; Vol. 9, No. 8. See the NIHR Journals Library website for further project information.
Criteria for inclusion in the Health Services and Delivery Research journal

Reports are published in Health Services and Delivery Research (HS&DR) if (1) they have resulted from work for the HS&DR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

HS&DR programme

The HS&DR programme funds research to produce evidence to impact on the quality, accessibility and organisation of health and social care services. This includes evaluations of how the NHS and social care might improve delivery of services.

For more information about the HS&DR programme please visit the website at https://www.nihr.ac.uk/explore-nihr/funding-programmes/health-services-and-delivery-research.htm

This report

The research reported in this issue of the journal was funded by the HS&DR programme or one of its preceding programmes as project number 13/54/55. The contractual start date was in June 2015. The final report began editorial review in June 2018 and was accepted for publication in April 2019. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HS&DR editors and production house have tried to ensure the accuracy of the authors’ report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health and Social Care. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health and Social Care.

© Queen’s Printer and Controller of HMSO 2021. This work was produced by Reynish et al. under the terms of a commissioning contract issued by the Secretary of State for Health and Social Care. This issue may be freely reproduced for the purposes of private research and study and extracts (or indeed, the full report) may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

Published by the NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Prepress Projects Ltd, Perth, Scotland (www.prepress-projects.co.uk).
NIHR Journals Library Editor-in-Chief

Professor Ken Stein  Professor of Public Health, University of Exeter Medical School, UK

NIHR Journals Library Editors

Professor John Powell  Chair of HTA and EME Editorial Board and Editor-in-Chief of HTA and EME journals. Consultant Clinical Adviser, National Institute for Health and Care Excellence (NICE), UK, and Professor of Digital Health Care, Nuffield Department of Primary Care Health Sciences, University of Oxford, UK

Professor Andrée Le May  Chair of NIHR Journals Library Editorial Group (HS&DR, PGfAR, PHR journals) and Editor-in-Chief of HS&DR, PGfAR, PHR journals

Professor Matthias Beck  Professor of Management, Cork University Business School, Department of Management and Marketing, University College Cork, Ireland

Dr Tessa Crilly  Director, Crystal Blue Consulting Ltd, UK

Dr Eugenia Cronin  Senior Scientific Advisor, Wessex Institute, UK

Dr Peter Davidson  Consultant Advisor, Wessex Institute, University of Southampton, UK

Ms Tara Lamont  Senior Scientific Adviser (Evidence Use), Wessex Institute, University of Southampton, UK

Dr Catriona McDaid  Senior Research Fellow, York Trials Unit, Department of Health Sciences, University of York, UK

Professor William McGuire  Professor of Child Health, Hull York Medical School, University of York, UK

Professor Geoffrey Meads  Emeritus Professor of Wellbeing Research, University of Winchester, UK

Professor James Raftery  Professor of Health Technology Assessment, Wessex Institute, Faculty of Medicine, University of Southampton, UK

Dr Rob Riemsma  Reviews Manager, Kleijnen Systematic Reviews Ltd, UK

Professor Helen Roberts  Professor of Child Health Research, UCL Great Ormond Street Institute of Child Health, UK

Professor Jonathan Ross  Professor of Sexual Health and HIV, University Hospital Birmingham, UK

Professor Helen Snooks  Professor of Health Services Research, Institute of Life Science, College of Medicine, Swansea University, UK

Professor Ken Stein  Professor of Public Health, University of Exeter Medical School, UK

Professor Jim Thornton  Professor of Obstetrics and Gynaecology, Faculty of Medicine and Health Sciences, University of Nottingham, UK

Please visit the website for a list of editors: www.journalslibrary.nihr.ac.uk/about/editors

Editorial contact: journals.library@nihr.ac.uk